

Public Health Committee Hearing
February 6, 2009
Raised House Bill No. 6263
An Act Requiring New Infant Health Screening for Cystic Fibrosis
By: Erin E. Jones, March of Dimes

Good Afternoon Members of Congress. My name is Erin Jones and I am here today representing the March of Dimes Connecticut Chapter in support of **S.B No. 6263, An Act Requiring New Infant Health Screening for Cystic Fibrosis.**

The March of Dimes supports comprehensive NBS for every baby born in the U.S. and its territories for conditions that meet the following criteria: there is a documented benefit to the affected infant from early detection and there is a reliable screening test that enables early detection from newborn blood spots or other means. March of Dimes recommends screening all newborns for 29 treatable conditions recommended in a 2004 report by the American College of Medical Genetics (ACMG) to the Federal Health Services Resources Administration (HRSA). The March of Dimes supports parents' rights to be promptly and thoroughly informed about their babies' screening results, and supports expansion of health care provider education programs. NBS programs should include high quality screening tests with the state-of-the-art technology, trained personnel, and resources for timely follow-up and program evaluation.

In Connecticut, mandatory testing for Cystic Fibrosis (CF) is still not required by law. CF is a life threatening genetic disease that causes mucus to build up and clog some organs in the body, particularly in the lungs and pancreas. When the mucus clogs the

lungs, it can make breathing very difficult. The thick mucus also causes bacteria to get stuck in the airways, which causes inflammation and infections that leads to lung damage. Early diagnosis and treatment for CF through newborn screening is critically important because of the benefits, a better chance for improved growth, improved lung functioning, reduce hospital stays and a longer life.

Newborn Screening is done by testing a few drops of blood, usually from a newborn's heel, before hospital discharge. A positive result does not always mean the infant has the disorder. If the screening result is positive, the infant is re-tested through a series of tests, to confirm a positive screen, and then given treatment as soon as possible.

Connecticut has made great strides in advocacy and awareness in the last few years. But today, Connecticut still only requires screening for 28 or 29 core conditions.

The March of Dimes Connecticut Chapter asks for your support in passing SB. No. 569 and mandating that every newborn be screened for Cystic Fibrosis and give these children with the disease the best chance for a healthy future.